



New Hampshire
Department of Health and Human Services

NH Medicaid Care Management
Stakeholder Feedback

October 6, 2011

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Due to their size, appendices are not included with this report but may be downloaded separately.

“Treat me like a person, not like a number.”

Background

At the direction of the New Hampshire Legislature, the Department of Health and Human Services is preparing to transition the state’s Medicaid Program from a fee for service model to a care management system.

The Department engaged Louis Karno and Company Communications and Pontifex Consulting to develop and implement a stakeholder engagement process in order to hear from program users, families and caregivers, providers and other indirect stakeholders what they thought would make the transition successful and what could make it fail.

- We held a day-long systems mapping session for the Department’s Care Management Program Design Team and a several outside stakeholders and used this information to structure a series of 6 facilitated public forums around the state. Approximately 450 people participated in the forums.
- With the help of human service agencies around the state we held 10 invitation-only consumer-oriented focus groups to hear directly from people we might not ordinarily hear from. Focus groups averaged 8-10 participants.
- We conducted an online survey to which 826 people responded.
- In addition the Department received letters and emails from a number of organizations and individuals.

We provided the Department with updates after each session and interim reports during the course of the stakeholder outreach effort.

All direct quotes used in this report are from focus group participants whose confidentiality was assured.

“A lot of my time is spent advocating for services, asking for services, trying to get services. This is time that I would rather have spent caring for my family member.”

Summary

Public Forums

The forums were designed to find out **how the new Care Management Program could:**

- Maximize program user and caregiver quality of life and health.
- Develop highly informed program users and caregivers.
- And create highly satisfied providers.

Both users/caregivers and providers suggested that **to maximize quality of life and health**, the system needed to:

- Be patient-centered and community based.
- Ensure decision-making is done through patient-provider interactions (not gatekeeper).
- Be prevention-focused.
- Ensure adequate local access (transportation if needed).

Users/caregivers asserted **they would be better informed if:**

- They were involved in implementation of new system.
- Points of contact were knowledgeable.
- Multiple media was used.
- Language was clear (and in native language for those where English is not primary).

Providers would be satisfied if:

- The system is patient-centered.
- Reimbursement is adequate/fair.
- Clients are satisfied.
- Healthy, behavioral health services were included.
- Paperwork/red tape was minimized.

“Why do you make it so hard for me to keep my mother at home? It would be a lot easier for me to turn her over to the state — and a lot more expensive.”

Focus Groups

The focus groups were designed to bring together program users, family members and caregivers who might not ordinarily participate in a public session and to facilitate a discussion about their hopes, fears and suggestions for the new Medicaid program.

Consumer groups targeted included:

- People with physical disabilities
- People with severe mental health issues
- People with substance abuse issues
- People with developmental disabilities
- The elderly who need long-term care assistance
- Low-income people and people who receive public assistance
- People with limited English speaking ability or cultural barriers to health access.

While our focus group interview questions differed from those used at the forums, **feedback on the Medicaid program and concerns expressed about a transition to a care management system tracked both what we heard at the forums and feedback from the online survey** that was conducted as a part of the engagement process.

In general, the program users we spoke with who use the Medicaid program sporadically (which tend to be low-income women and children) are satisfied with the current program and less fearful about any changes to it. Those who rely on it for acute or chronic care (long-term care, developmental disability or mental health services) are much more skeptical about the transition to care management. They see it as **an attempt by the state to save money; not to increase the quality of care program users currently receive.**

They are also greatly **concerned about the transition’s potential effect on the community-based organizations**, like the state’s system of developmental disability agencies and its community-based mental health agencies, which most view as providing them with personal, effective and cost-effective support and services.

“We have not met a bad person in the whole system. But it’s complicated, overwhelming, convoluted. We get different answers from different people. You head down one path only to find you’ve got incorrect information.”

What program users want in the Managed Care Program

Customer service

- To be **treated like people** and not like statistics.
- To be able to **talk with a person** who knows what they are talking about -- not voice mail systems. To get calls back when they leave a message. To get the same definitive answer to a question about eligibility or coverage no matter who they ask.
- To deal with program **vendors who know the state** and its geography so that they know why it might not make sense to travel 70 miles to Community A for services when you live next to Community B and they are available there.

Quality

- To see the **quality of services people receive increased**, not decreased.
- **Choice** in care.
- To make sure that **doctors call the shots** about what care is needed, not the managed care vendor.
- A **focus on preventive care**, including a **dental benefit for adults** that includes cleanings and fillings not just extractions.
- To maintain their **current consistency of care** through any transition. Don’t disrupt physician-patient relationships, medications, agency relationships that are successful and in place.
- To have **medical providers receive fair and adequate reimbursement** so that they will want to provide services to people who are covered by Medicaid.
- To maintain the ability to use **personal care attendants** for those with physical disabilities.
- To maintain assistance with **transportation expenses and services**.
- To include a **substance abuse treatment** benefit.
- More support for **elder day care** programs.
- To maintain **access to medical specialists** and other health care services **outside the state** (in particular MA, VT, ME).

Administration

- To establish a solid, rapid **grievance process** so that when care is denied appeals don't drag on and a fair, impartial decision is made.
- To **allow DHHS to be a managed care vendor**. People feel that they, and the legislature, will maintain more control over the administration of the NH Medicaid Care Management program if DHHS administers it.
- **Reduced paperwork**.
- **Reduced caseloads** for DHHS caseworkers, who people view as so overloaded they can't humanly provide effective service. (Can't reach caseworkers on the phone. Voicemail boxes are full. If not full, messages are generally not returned.)
- A **simplified "spend down"** eligibility process. It is currently confusing, frustrating and inefficient.
- **Simplify and streamline the Medicaid application process and recertification process**. Recertification is particularly frustrating for parents of children who have genetic conditions which will never change and who will always need and qualify for services. A simple statement from a physician or medical home attesting to the fact that the person's health situation hasn't changed should be sufficient.
- To **allow community-based agencies** like mental health centers and area agencies **to contract and serve as medical or health homes**.
- To have the state establish an independent, family centered, **state-wide quality assurance body** to provide oversight of managed care vendors.

Communication

- **Better (clear, concise) communication** about how to navigate the system and what is covered by Medicaid and what is not. This needs to be delivered consistently both in print, electronically and in person.
- Educational materials in **easy to understand language**, and for those with limited English proficiency, written in their language (Spanish, Portuguese, etc.).
- Educational materials available in a **variety of forms**, on the web, but also in print and mailed directly to them at home.
- Educational materials **on par with the federal Medicare program** which people say does a much better job of educating consumers and training human service agency staff about how the program works and what is covered than does Medicaid.
- Better communication and **coordination between agencies**, including Medicaid and Medicare.
- More effective **personal help** in navigating the Medicaid system, particularly for those who are new to it.

Online Survey

We conducted an online survey from September 16—October 5, receiving 826 responses and 701 completed surveys (84.7% completion rate). We received:

- 27 responses from program users (3%)
- 273 from family members or caregivers of someone using Medicaid (33%)
- 356 from health care and human service providers (43%)
- 170 from people who do not provide or receive services but who are interested in the program (21%).

Survey responses tracked forum and focus group feedback. However, in addition to the types of questions we asked in the forums and focus groups we asked survey respondents questions about their outlook for the new program and what role personal responsibility played in improving the quality of peoples lives and health through the Medicaid program.

Optimism and personal responsibility

How optimistic are you that the new care management program will be an improvement over the new one? *Most are not.*

- 41% of program users are not at all optimistic.
- 56% of families and caregivers are not at all optimistic.
- 43% of providers are not at all optimistic.
- 21% of indirect stakeholders are not at all optimistic.

How concerned are you about the state's ability to fund the new program? *Most are concerned.*

- 87% of program users are very or extremely concerned.
- 71% of families and caregivers are very or extremely concerned.
- 77% of providers are very or extremely concerned.
- 74% of indirect stakeholders are very or extremely concerned

How important people believe that taking personal responsibility is for people to improve the quality of their lives and health through the state's Medicaid program. *Most think it is important.*

- 81 % of program users believe that it is very or extremely important.
- 70% of families and caregivers believe that it is very or extremely important.
- 67% of providers believe it is very or extremely important.
- 64% of indirect stakeholders believe that it is very or extremely important.

Due to the length and complexity of the survey and the ease with which the results may be viewed and understood graphically, its summary is presented in Appendix 3 (27 pages, does not include open-ended responses) and Appendix 4 (148 pages, includes open ended responses). Appendices may be downloaded separately from this report.

Public Forums

As part of the stakeholder engagement process, Louis Karno & Company and Pontifex Consulting facilitated six public forum events over the course of three weeks in September 2011. These forums were:

Keene – September 13 at Keene Public Library
Nashua – September 14 at Nashua Community College
North Country* – September 21 at Granite State College, Littleton
Somersworth – September 22 at Goodwin Community Health, Somersworth
Manchester – September 23 at Manchester Health Department
Concord – September 29 at IBEW Concord

* Facilitated from Gregg Public Safety Academy with connected sites at DMHC Lebanon and AVH Berlin

The purpose of these forums was to **provide the public with an opportunity to learn about the current proposed managed care approach** for Medicaid and for the **public to provide feedback and input** the department will use **in developing the RFP** for potential vendors.

Forum agendas

All forums used a similar agenda.

1. Introduction by spokesperson for the department.
2. Understand the context for meeting.
3. Develop common understanding of systems and the need for multiple perspectives.
4. Small group exercises (split into two types of groups: 1) program users/caregivers and 2) providers).
5. Small groups brainstormed answers to strategic questions specific to their group.
6. Groups voted to select most important answers to each question.
7. Large group report out per question – each group provided their most important answers.
8. Wrap up, including recommendation to complete online survey.

In Keene, the groups were asked to answer four questions. Based on feedback from participants, the number of questions for Manchester was reduced from four to three, and ultimately participants answered only two questions during the North Country forum and for each forum thereafter. We determined that we could gather similar information with fewer questions. This allowed the participants to have richer conversations in small groups, and the opportunity to ask about common themes in the large group.

Objective of exercises

Based upon a mapping exercise held with the Design Team and a few external stakeholders on September 7th, we were able to develop a set of focused questions to get at the most essential aspects of a managed care approach to NH Medicaid as they relate to program users/caregivers and providers. As a result of the mapping session, we were able to segment program users by two attributes:

1. Quality of Life/Health
2. Level of System/Health Knowledge (Literacy)

For simplicity, this means program users could be considered as being in one of four “buckets” (shown in the 2X2 table).

Assuming an effective goal is having as much of the population as possible in the Maximized QoL and High Knowledge bucket (upper right), all questions for program users and caregivers (and most of those for providers) asked either how to move people up to higher QoL or how to move over to higher Knowledge.

In the first two forums we asked participants to expand on the concept of what defined Maximized Quality of Life/Health. Some responses are shown in the *Participants Define Maximized Quality of Life/Health* box. In the final four forums, in order to provide more time to delve into questions regarding how to accomplish various outcomes, we showed participants these responses and asked them to answer the remaining questions based upon similar definitions of Quality of Life/Health.

1. Quality of Life/Health

Maximized Quality of Life and Health is living in least restricted environment possible, maximizing social and emotional well-being, a life that's as comfortable as possible and with the least invasive treatments

2. Level of System/Health Knowledge (Literacy)

Understanding the system enough in order to maximize its benefits AND understanding your health in a way to maximize behavior for navigating/using system and personal prevention

2X2 Matrix

Segment Program Users as...	Low Health System Knowledge AND Low Personal Health Knowledge/ Literacy	High Health System Knowledge AND High Personal Health Knowledge/ Literacy
Maximized Quality of Life / Health		
Lower Quality of Life / Health		

Participants Define Maximized Quality of Life/Health

- Opportunity to **live as fully** as people not on Medicaid
- All encompassing **health and wellness**
- **Resources** for every recipient
- **Choice** of Providers and Availability of Comprehensive Array of Services directed by the recipient
- **Independence** and relationships built on trust
- **Continuity and constancy** of care...right care right time
- **Self Determination**
- **Affordability**
- **Integration** of Services at all Levels – Breaking Down of Silos at Federal, State, and Provider, and Individual Level
- Ability to **reach maximum potential/goals**
- **Access to & affordability** of quality care
- Comprehensive, well coordinated, quality care that is evidence-based and comparable. Self directed and self-fulfilling

Question 1: What must a care management system provide to [increase](#) the number of NH's Medicaid population living a [high](#) (maximized) [quality life/health](#)?

Program Users/Caregivers

Program Users/Caregivers responded to this question with several responses based on: access, choice, decision-making by patients with physician and local service provider.

- Local decision-making (physician and local providers).
- Community based.
- Person/patient centered.
- Prevention focused.
- Adequate funding.
- Access to integrated care (physical, mental, social).
- Access to timely information.
- Timely and fair conflict resolution process – oversight.

Providers

When asked a similar question, but focusing on what they believe providers must be able to do in a managed care system, providers have said they could increase the number with Maximized Quality of Life/Health with:

- Decision-making by providers and patients – no gatekeepers.
- Person/patient centered.
- Prevention focused.
- Timely information.

Detailed responses to question 1 for each group from all six forums can be found in Appendix 1 which may be downloaded separately from this report.

Question 2: In a care management program, what must happen in order to [create knowledgeable](#) and [informed program users](#) and caregivers?

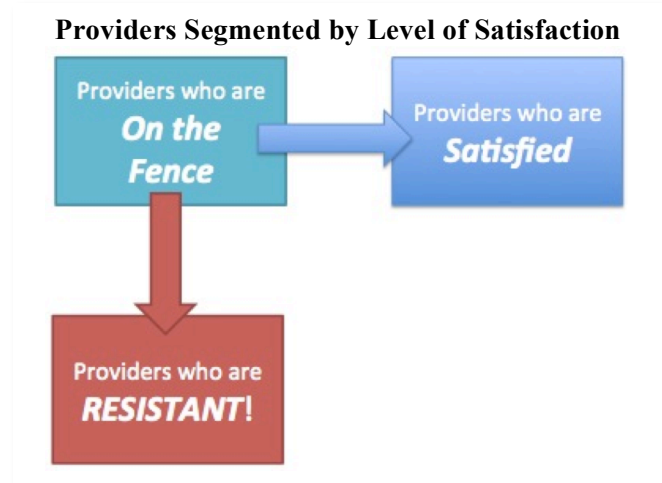
When asked what would move Program Users and Caregivers into High Knowledge and High Literacy, Program Users and Caregiver responses include:

- Clear, concise communication language (including in language of user / caregiver).
- Multiple media including Web based delivery and newsletters.
- Knowledgeable “points of contact” – providers and oversight.
- Patient centered.
- Training for everyone.
- Local control.
- Reduce system complexity.

Detailed responses to question 2 for each program user / caregiver group from all six forums can be found in Appendix 1 which may be downloaded separately from this report.

Provider perspective

There is another important consideration to address in phasing in a managed care approach. When a new system is implemented, providers will fall along a continuum of satisfaction. Most (it is hoped!) will be in the middle in what can be termed *On the Fence*. *On the Fence* providers are those who aren't sure if this will be good or bad – will it serve their needs and those of their clients? Over time, those on the fence will move into the *Satisfied* bucket, or worse, could move into the *Resistant* bucket. *Satisfied* providers – it is assumed – will deliver better service, increase customer satisfaction, and have a “knowledge focus”. *Resistant* providers will create negative consequences to the system. They will provide lower quality care, go through the motions, add administrative overhead, and perhaps seek litigation. Ultimately, they may cease delivering services.



The main provider **goal** upon implementation would be to (as rapidly as possible!) **move *On the Fence* providers to being *Satisfied***. When new systems are implemented it is often a footrace between getting supporters of that new system and those actively fighting against it. If this footrace is lost, many negative dynamics are often set in motion.

Question 3: In a care management program, what must happen in order to create **satisfied providers** instead of **dissatisfied (or Resistant)** providers?

When asked in public forums, Providers have said the following are important to moving into the *Satisfied* bucket – and remaining there!

- Patient centered approach with local control.
- Adequate reimbursement.
- Client satisfaction and safety.
- Integrating behavioral health into primary care.
- Eliminate paperwork / hassles.
- Increase service access.
- Communication & transparency.

Detailed responses to question 3 for each program user / caregiver group from all six forums can be found in Appendix 1 which may be downloaded separately from this report.

“Make sure that people are not put backwards by having to change doctors or medications.”

Consumer Focus Groups

Listening to people who use Medicaid

As part of NH Department of Health and Human Services Medicaid care management program stakeholder engagement process, Louis Karno & Company Communications conducted nine, invitation-only, consumer-oriented focus groups and a set of ten, one-on-one interviews with people who used the state’s Medicaid program or who had children or family members who use it.

The focus groups were held September 15—October 1 and were organized in conjunction with local human service agencies that recruited participants for us from among their consumer and clients. Focus groups averaged 8-10 participants.

Consumer groups targeted included:

- People with physical disabilities.
- People with severe mental health issues.
- People with substance abuse issues.
- People with developmental disabilities.
- The elderly who need long-term care assistance .
- Low-income people and people who receive public assistance.
- People with limited English speaking ability or cultural barriers to health access.

Partner agencies had difficulty in organizing focus groups for the low-income, TANF population and so we worked with a community health center to interview people one-on-one who were visiting the center for WIC visits.

We also helped to organize and attended the six facilitated public forums held around the state for program users, families and caregivers and providers as well as other stakeholders. We found that while our focus group interview questions differed from those used at the forums, **feedback on the Medicaid program and concerns expressed about a transition to a care management system tracked both what we heard at the forums and in the on-line survey** that was conducted as a part of the engagement process.

We particularly want to thank the following organizations for their help in assisting us with the focus groups:

- Easter Seals, Manchester
- New Futures
- Mental Health Center of Greater Manchester
- Foundation for Seacoast Health Community Campus, Portsmouth
- Granite State Independent Living
- Dartmouth Hitchcock Medical Center, Lebanon
- Androscoggin Valley Hospital, Berlin
- Lamprey Health Center, Nashua
- Community Support Network
- North Country Education Services, Gorham
- Community Bridges, Concord
- Goodwin Health Center, Somersworth
- Community Partners: Behavioral Health and Developmental Services of Strafford County, Dover
- Northern Human Services, Littleton
- ServiceLink Sullivan County, Claremont
- ServiceLink Coos County, Berlin/Gorham
- ServiceLink Rockingham County, Salem
- Silverthorne Adult Day Center, Salem

The NH Medicaid Program

Medicaid is the public health insurance program that is paid for equally by each state and the federal government. It is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Medicaid is a state administered program and each state sets its own guidelines regarding eligibility and services.

There are currently more than 165,000 people in New Hampshire who receive health care services paid for by the NH Medicaid program. In terms of understanding the feedback we received from program users, it may be **useful to think of the state's Medicaid users as falling into two groups.**

The first group are low-income. Approximately 60% of the state's Medicaid users are low-income children (96,000); 15% are low-income adults (26,000). Together this group represents **74% of the state's Medicaid population** but the health services this group uses each year represents **30% of total state Medicaid expenditures.**

The second group is comprised of people who have **acute or chronic medical or mental health needs** and who receive intensive health care services over a long period of time -- perhaps over the course of their entire lives. They may qualify because they or their families are low-income, or receive income eligibility waivers based on their health situations. This group includes people with physical disabilities (10,600), people with mental disabilities (13,300) and elderly people (11,600).

This second group represents 25% of the state's Medicaid population but due to their acute care needs **uses approximately 70% of total state Medicaid expenditures.**

“People like *me* count on *you*.”

Focus Group Summary

Group one – low-income

In general, the people we spoke with who fell into the first group of program users use services paid for the Medicaid program sporadically. Many that we spoke with were enrolled in Medicaid when they were pregnant and shortly thereafter, but are not now eligible and have no health insurance. They have children enrolled in the Healthy Kids program who have well-child visits, antibiotics and other basic care paid for by the program.

These program users generally are satisfied with the current program (except for some paperwork issues) and feel that it works well, except for the lack of a preventative dental benefit for adults, and the difficulty in getting specialized care if needed. They are grateful that their children are covered. Their primary fear of any change to the program is that administrative issues will become more cumbersome.

We did ask members of this group about their **use of a hospital emergency department**. Most reported using it 1-2 times in the last year, primarily for medical care for their children. The more children they had, the more frequently it seemed they were likely to use the ER.

Group two – chronic care needs

In general, people who fell into the second group of program users, whether they be direct recipients of services, or family members or caregivers of program users, **are deeply suspicious of the state’s motivation** to transition to care management **and fearful of its impact** on their personal health situation or a loved one’s. Most of the people who receive services live at home and their families want to care for them at home.

These people are much more knowledgeable about the transition than those in group one.

They see care management as **an attempt by the state to save money; not to increase the quality of care program users currently receive**. They are deeply concerned that changes to the Medicaid program could interrupt the delicate balance of stability that they, or their loved ones, have achieved with the help of the current system.

The people who receive these services face substantial challenges and have struggled for years at great personal effort to get to the point they are today. Any interruption in the continuity of care they currently receive, whether it be a physician-patient relationship, the loss of a personal care attendant, or a requirement to switch from a brand name drug that keeps them stable to an untried generic could trigger an insurmountable setback. They have a lot to lose in a Medicaid program redesign, and from their perspective, not much to gain.

They are also greatly **concerned about the transition's potential effect on the community-based organizations**, like the state's system of developmental disability agencies and its community-based mental health agencies, which most view as providing them with personal, effective and cost-effective support and services.

Members of this group often have Medicaid as a supplement to either private insurance or Medicare. Those that did appeared to be **much more highly satisfied** with the current program than those who have it as their primary source of health coverage.

Many of the people representing the second group of Medicaid program users whom we spoke with in our focus groups said that they thought that our focus groups were merely window dressing and were **openly skeptical that their feedback would have any impact on the new Medicaid program's design**. When we assured them that **the Department was truly interested in their input** and that they had a real opportunity to shape its design, even the most skeptical provided solid suggestions and at the conclusion of the groups thanked us for the opportunity to be heard.

“I am active in my own recovery. I don’t always like it, it doesn’t often feel fair. I didn’t ask for this. I didn’t want to be born this way.”

What consumers want in the new Medicaid Program

Customer service

- To be **treated like people** and not like statistics.
- To be able to **talk with a person** who knows what they are talking about -- not voice mail systems. To get calls back when they leave a message. To get the same definitive answer to a question about eligibility or coverage no matter who they ask.
- To deal with program **vendors who know the state** and its geography so that they know why it might not make sense to travel 70 miles to community A for services when you live next to community B and they are available there.

Quality

- To see the **quality of services people receive increased**, not decreased.
- **Choice** in care.
- To make sure that **doctors call the shots** about what care is needed, not the managed care vendor.
- A **focus on preventive care**, including a **dental benefit for adults** which includes cleanings and fillings not just extractions.
- To maintain their **current consistency of care** through any transition. Don’t disrupt physician-patient relationships, medications, agency relationships that are successful and in place.
- To have **medical providers receive fair and adequate reimbursement** so that they will want to provide services to people who are covered by Medicaid.
- To maintain the ability to use **personal care attendants** for those with physical disabilities.
- To maintain assistance with **transportation expenses and services**.
- To include a **substance abuse treatment** benefit.
- More support for **elder day care** programs.
- To maintain **access to medical specialists** and other health care services **outside the state** (in particular MA, VT, ME).

Administration

- To establish a solid, rapid **grievance process** so that when care is denied appeals don't drag on and a fair, impartial decision is made.
- To **allow DHHS to be a managed care vendor**. People feel that they, and the legislature, will maintain more control over the administration of the NH Medicaid Care Management program if DHHS administers it.
- **Reduced paperwork**.
- **Reduced caseloads** for DHHS caseworkers, who people view as so overloaded they can't humanly provide effective service. (Can't reach caseworkers on the phone. Voicemail boxes are full. If not full, messages are generally not returned.)
- A **simplified "spend down"** eligibility process. It is currently confusing, frustrating and inefficient.
- **Simplify and streamline the Medicaid application process and recertification process**. Recertification is particularly frustrating for parents of children who have genetic conditions which will never change and who will always need and qualify for services. A simple statement from a physician or medical home attesting to the fact that the person's health situation hasn't changed should be sufficient.
- To **allow community-based agencies** like mental health centers and area agencies **to contract and serve as medical or health homes**.
- To have the state establish an independent, family centered, **state-wide quality assurance body** to provide oversight of managed care vendors.

Communication

- **Better (clear, concise) communication** about how to navigate the system and what is covered by Medicaid and what is not. This needs to be delivered consistently both in print, electronically and in person.
- Educational materials in **easy to understand language**, and for those with limited English proficiency, written in their language (Spanish, Portuguese, etc.).
- Educational materials available in a **variety of forms**, on the web, but also in print and mailed directly to them at home.
- Educational materials **on par with the federal Medicare program** which people say does a much better job of educating consumers and training human service agency staff about how the program works and what is covered than does Medicaid.
- Better communication and **coordination between agencies**, including Medicaid and Medicare.
- More effective **personal help** in navigating the Medicaid system, particularly for those who are new to it.

Outlines of the feedback we received during each of the consumer-oriented focus groups are included in this report as Appendix 2 which may be downloaded separately from this report.

About the firms

Pontifex Consulting has a depth of expertise in helping private, public and non-profit organizations build their capacity to think and act systemically. It often works in partnership with the Systems Thinking Collaborative (STC). The firm provides practical experience to help organizations apply the principles of Systems Thinking to achieving their strategic goals. pontifexconsulting.com

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